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CHAPTER 7

Comfort goal of care and end-of-life outcomes in dementia: A prospective study

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ABSTRACT

Background: Many people with dementia die in a nursing home. A comfort care goal may be beneficial. Little research has examined the relationship between care goals and outcome.

Aim: To investigate whether family satisfaction with end-of-life care and quality of dying is associated with whether or not dementia patients have a comfort goal shortly after admission.

Design and setting: Prospective data collection from 28 long-term care facilities (the Dutch End of Life in Dementia study). We included 148 patients who died after prospective follow-up. Main outcomes were family satisfaction (End-of-Life in Dementia– Satisfaction with Care scale; range: 10–40) and quality of dying (End-of-Life in Dementia-Comfort Assessment in Dying; range: 14–42). We performed generalized estimating equations regression analyses to analyze whether these outcomes are associated with a comfort goal established shortly after admission compared with another or no care goal as reported by the physician.

Results: Families of patients were more satisfied with end-of-life care when a comfort goal was established shortly after admission. We found this pattern only for patients who died within 6 months of admission (adjusted b: 4.5; confidence interval: 2.8, 6.3 vs –1.2; confidence interval: –3.0, 0.6 for longer stay). For quality of dying, no such association was found.

Conclusion: We found that family satisfaction with care is related to a comfort care goal shortly after admission, but quality of dying did not. Establishing a comfort goal at an early stage may be important to the family. Advance care planning interventions should be studied for their effects on patient and family outcome.

INTRODUCTION

Many people die in nursing homes (NHs) or other institutional long-term care settings.¹ Admission to a NH provides the opportunity to assess or evaluate care goals with patients, family, and professional caregivers. This may be part of advance care planning (ACP) which guides the care and treatment in later phases of the dementia.^{2–5} The family has an important role in ACP with dementia, as many NH patients with dementia lose decisional capacity. Early in the course of dementia, treatments primarily intended to prolong life may be indicated. With the progression of the dementia, a main care goal aimed at comfort or quality of life—as in palliative care—may become more appropriate.^{2,6–8}

The relationship between care goals and outcome has not been studied extensively so far.⁹ Most studies employed a retrospective design,¹⁰ or studied care systems. For example, family of people with dementia in the United States reported higher satisfaction with end-of-life care and better quality of dying when hospice care was provided.^{11,12}

The current study investigates prospectively whether family satisfaction with end-of-life care and quality of dying of dementia patients is associated with a comfort care goal established shortly after admission compared with no such goal.

METHODS

In the Dutch End of Life in Dementia (DEOLD) study, patients' families and elderly care physicians provided data about treatment, care, and outcomes, including family satisfaction with care and quality of dying, from admission to the NH until death or conclusion of data collection. The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center.¹³

Study design

NHs were recruited purposefully nationwide, aiming at variability in outcome and representativeness for the Netherlands.¹³ A total of 17 NH organizations covering 28 facilities prospectively recruited 372 newly admitted dementia patients between January 2007 and July 2009. Follow-up for data elements including end-of-life outcomes lasted until July 2010. During the data collection, 218 of 372 patients died. We aimed at ≥ 160 after-death reports on patients for sufficient power with hierarchical modeling.¹³ Physicians and families (the contact persons for professionals) completed baseline assessments 8 weeks after admission. The 8-week time frame of the baseline assessment was chosen because it was close to the Dutch legal standard of the 6-week limit for establishing a plan of care after

admission.¹⁴ This dynamic plan of care includes main goals to be achieved with the care and treatment.¹⁵

A total of 35 patients died within that time period and were excluded, as no baseline assessment was available. Data on care goals were incomplete for 5 of the 183 patients with a physician baseline assessment, and for 30 patients, no after-death assessment was completed by their family. Reasons for not completing the after-death assessment included, for example, family were too emotional and family moving without providing new address. For the current analyses, we included 148 patients who died during the data collection period, who stayed (survived) in the NH for at least 8 weeks, had a prospective physician baseline assessment with complete data on care goals, and a family after-death assessment.

Data collection

Written questionnaires were completed 8 weeks after admission (baseline), every 6 months after that (semi-annually), and after death (family after 2 months; physicians within 2 weeks) for patients whose families had consented to participate upon admission. In the Netherlands, after NH admission, care is transferred from the general practitioner to an elderly care physician who is on the staff. Elderly care medicine is an officially recognized medical discipline, and physicians are trained in a special postgraduate training program.¹⁶

Measures

Family satisfaction with care and quality of dying as outcomes. We used the family evaluations to avoid a physician-reported outcome of physicians' care goals and because of their intrinsic value of family perceptions in palliative care. Family satisfaction with care and family perception of quality of dying are important outcomes in palliative care because families have an important role at the end of life, and they live on with the memories after the patient dies.^{10,17} The End-of-Life in Dementia (EOLD) instruments, which were developed for family evaluations of dementia patients after death, were used to evaluate satisfaction with care and quality of dying.¹⁸ We used the EOLD-Satisfaction with Care (EOLD-SWC) to measure satisfaction with care in the last month of life as the family perspective on the quality of end-of-life care, and the EOLD-Comfort Assessment in Dying (EOLD-CAD) to measure comfort in dying as part of quality of dying (Box 1).¹⁹ These instruments had better psychometric properties and were more user friendly than other instruments.^{20,21}

Box 1. End-Of-Life in Dementia (EOLD) scales

EOLD-Satisfaction With Care (EOLD-SWC)

The 10 EOLD-SWCC items are scores a scale of 1 (totally disagree) to 4 (totally agree). Items scores were summed and the overall score ranges from 10 to 40. Item scores are reverse coded if necessary so higher scores reflect higher satisfaction.

Example items EOLD-SWC: Think about the doctors, nurses, nurse aids and other staff that you came into contact with in *the last week of life*: how strongly do you feel the following statements reflect your experience? (strongly disagree, disagree, agree, strongly agree)

- * I felt fully involved in all decision making
- * I always knew which doctor or nurse is in charge of my family/loved one's care
- * I felt that all medication issues were clearly explained to me

EOLD-Comfort Assessment in Dying (EOLD-CAD)

The EOLD-CAD consists of 14 items, scores on a scale of 1 (not at all) tot 3 (a lot). Items are summed to calculate an overall score between 14 and 42. Items are reverse coded if necessary so higher scores reflect more comfort.

Example items EOLD-CAD: When you were present *during the dying* (process) of your family/loved one, and you think about your family/loved one's physical and emotional state, can you please indicate to what extent he or she experienced the following as he or she was dying? (a lot, somewhat, not at all)

- * Discomfort
- * Choking
- * Fear
- * Peace

Main care goal. Physicians reported the main care goals during all assessments (questionnaires), and in this article, we report on the care goals at baseline. The main care goal was the single goal that took priority. The response options for care goals were “palliative care goal” (aimed at well- being and quality of life; irrespective of shortening or pro- longing of life), “symptomatic care goal” (aimed at well-being and quality of life; additional prolonging of life undesirable), “maintaining or improving functioning,” “life prolongation,” “other,” and “global care goals have not been established yet.” For regression analyses, we dichotomized, combining palliative and symptomatic care goals into a comfort care goal, versus the remaining options.

Covariates. To balance the groups of patients with and without a baseline comfort care goal, we adjusted for selected factors associated with having a baseline comfort care goal in other work²² and for patient gender and age, family member's highest completed educational level (combined into a four-level hierarchical variable representing relevant levels in the Netherlands), and length of stay. We adjusted for physician's judgment of illness severity and dementia severity, specific religious background, family's judgment about patient's competence to make decisions on medical treatments, whether the patient previously expressed wishes about medical treatments according to family, and physician's survival prediction of 1 year or less (see footnotes in Table 1 for measures and response options). We

refrained from adjustment with factors which are obviously associated with the delivered care or quality of care, such as family trust in the physician, which may mediate the associations we studied. Furthermore, we did not adjust for factors closely related to the independent variable of interest, that is, care goal, such as the family opinion that life prolongation is not preferred.

We also adjusted for length of stay as related to illness severity and/or short-term prognosis.²² Furthermore, higher family satisfaction with end-of-life care and quality of dying were reported when length of stay was longer.¹³ To examine whether length of stay interacted with care goal, we dichotomized length of stay into 6 months or less versus longer than 6 months and do not know. We selected a cut point of 6 months as enrollment of dementia patients in US hospice care—which also focuses on symptom control and quality of life—is based on a 6-month survival prediction.²⁸

Analyses

After imputing missing items with item means if appropriate (≤ 3 of 10 EOLD-SWC items and ≤ 4 of 12 EOLD-CAD missing),²⁹ an EOLD-SWC total score was available for 144 of the 148 patients and the EOLD-CAD for 83 of the 87 families who were present at death. To analyze associations adjusted for clustering of patients with 80 physicians, generalized estimating equations (GEE) regression analyses were performed. The dependent variables were family satisfaction with care (EOLD-SWC) and quality of dying (EOLD-CAD). A difference of 3 points is clinically meaningful.³⁰ This implies, for example, that 3 of 10 or 14 items improve 1 point. The independent variables were having a comfort care goal at baseline versus having another care goal or no goal, and the covariates described above. Confidence intervals (95% CI) were calculated, and the level of significance was 0.05. GEE was performed in three steps (Box 2). Additional analyses included t-tests and analysis of variance (ANOVA) to compare family and professional perspectives on quality of dying (mean EOLD-CAD), and patients with a length of stay ≤ 6 months and patient with a longer length of stay. All analyses were performed with IBM SPSS Statistics 20.0 (2011).

Box 2. Generalized Estimating Equations (GEE) regression analyses performed in three steps

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- Step 1 Unadjusted analyses were performed to determine whether family satisfaction with end-of-life care and quality of dying of patients with dementia is associated with a baseline comfort care goal compared with another care goal or no care goal.
- Step 2 We tested for interaction between having a baseline comfort care goal and length of stay (≤ 6 months or > 6 months). In case of significant interaction, we analyzed separately for the samples with length of stay ≤ 6 months, and > 6 months.
- Step 3 Analyses were performed adjusted for the covariates.^a
-

^a Missing items on the covariates ($\leq 1.4\%$ missing values) were imputed with appropriate means or a modus.

RESULTS

Table 1 shows patient and family baseline characteristics. Most of the patients were female (66.2%), their mean age was 84.9 years, and on average, they were mildly ill (mean 2.9). The mean length of stay was 1 year (standard deviation (SD): 0.7). A minority of patients (25.0%) had a physician's prediction of survival (1 year or less). Only 8.8% of the patients had a prediction of shorter than 1 month or 1–6 months, while one-third of all patients (33.8%) died within 6 months after admission (not in Table). For 60.8% of the patients, comfort was the main care goal shortly after admission (Table 1). At death, 89.0% of patients had a comfort care goal (not in Table).

Family satisfaction with end-of-life care and quality of dying

Figures 1 and 2 illustrate family satisfaction with end-of life care (EOLD-SWC) and family perspectives on quality of dying (EOLD-CAD) of patients dying with dementia, unadjusted for possible covariates. The mean EOLD-SWC score was 33.2 (SD: 4.7) and the mean EOLD-CAD score was 33.4 (SD: 5.9; totals in Figures 1 and 2). These mean scores did not differ between patients with and without a baseline comfort care goal (Table 2). Family perspectives on quality of dying (EOLD-CAD) did not differ significantly from professional perspectives (mean: 34.4, SD: 5.3, $p = 0.181$; not in Table).

Table 1. Characteristics patients and families at baseline

	Total (n=148)
<i>Patients with dementia</i>	
Age, mean (SD)	84.9 (6.2)
Female gender, %	66.2
Physician's judgment of illness severity, mean (SD) ^a	2.9 (2.0)
Dementia severity, mean BANS-S score by physician (SD) ^b	14.0 (4.2)
Physician's prediction of patient survival ^c , %	
Shorter than one month	1.4
One through six months	7.4
Seven through twelve months	16.2
More than one year	59.5
Don't know	15.5
Length of stay, %	
≤ six months	27.0
> six months	73.0
Any specific religious background ^d , %	75.5
Main care goal according to physician, %	
Comfort care goal	60.8
Palliative care goal	42.6
Symptomatic care goal	18.2
Maintaining or improving function	16.2
Life prolongation	1.4
Other	4.1
Global care goals had not been assessed yet	17.6
Family judgment about patient's competence to make decisions, %	
Not competent	71.4
Sometimes or partly competent	25.9
Competent	2.7
Patient's previously expressed wishes about medical treatments according to family, %	39.5
<i>Families</i>	
Educational level, %	
None or primary/elementary school	4.8
(High school preparing for) technical or trade school	53.4
High school preparing for Bachelor's or Master's degree	10.3
Bachelor's or Master's degree	31.5

^a "How sick is the patient now?; 1 = "not ill," 2-3 = "mildly," 4-5 = "moderately," 6-7 = "severely," and 8-9 = "moribund." (23,24); ^b BANS-S = Bedford Alzheimer Nursing Severity-Scale. Scores range from 7 ("no impairment") to 28 ("complete impairment"). A score of 17 and higher refers to "severe dementia." (25,26,27); ^c For the GEE regression analyses, we dichotomized, combining "shorter than one month," "one through six months," and "seven through twelve months" as one year or less versus the other categories.; ^d Protestant, Roman-Catholic, Humanist, other specified religious background.

We found a significant interaction between length of stay and baseline comfort care goal for family satisfaction with care ($p < 0.001$) and quality of dying ($p = 0.03$). In subsequent analyses, we therefore performed subgroup analyses according to length of stay. The families of patients who stayed in the NH 6 months or less ($N = 39/144$ with an EOLD-SWC score) were more satisfied with end-of-life care when a comfort care goal was established shortly after admission, as compared to when no comfort care goal was established ($b = 5.3$; CI: 2.8, 8.1; Figure 1 and Table 2).

This association between family satisfaction with end-of-life care and baseline comfort care goal was also statistically significant in adjusted analyses (Table 2). In addition, families of patients who had previously expressed wishes about medical treatments to someone were also statistically significantly more satisfied than families of patients who had not previously expressed wishes. When the length of stay was longer than 6 months, in unadjusted and adjusted analyses, there was no association between comfort care goal and family satisfaction with end-of-life care.

For patients who died within 6 months after admission, the quality of dying was worse for patients with a baseline comfort care goal than for patients without a baseline comfort care goal (-5.4 points; CI: $-9.9, -0.9$; Figure 2 and Table 2). However, after adjustment for possible covariates, this association was no longer statistically significant (-2.0 points; CI: $-6.6, 2.6$; Table 2). Furthermore, female patients and those more competent to make decisions on medical treatments had a better quality of dying. For patients who stayed in the NH more than 6 months, in unadjusted or adjusted analyses, we found no association with this outcome.

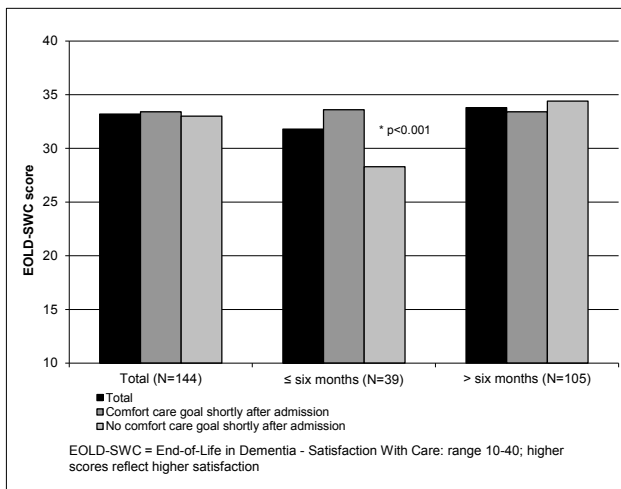


Figure 1. Family satisfaction with end-of-life care unadjusted for possible covariates

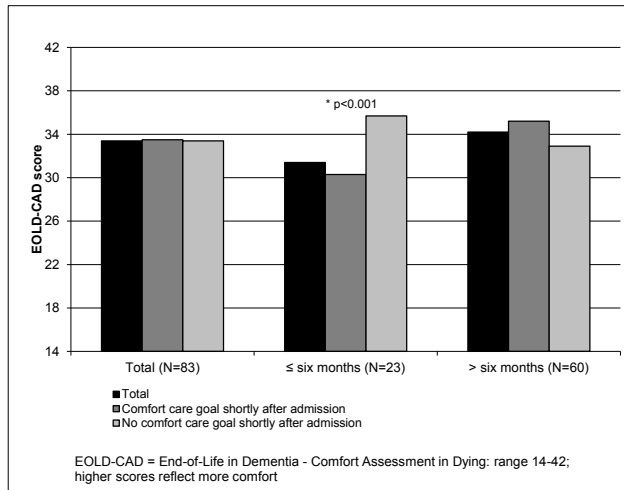


Figure 2. Family perspectives on quality of dying unadjusted for possible covariates

Table 2. Differences between a baseline comfort care goal and another care goal or no care goal for family satisfaction with end-of-life care (EOLD-SWC) and family perspectives on quality of dying (EOLD-CAD)

With comfort care goal:	EOLD-SWC	EOLD-SWC model, significant covariates	EOLD-CAD	EOLD-CAD model, significant covariates
	b (CI)		b (CI)	
Unadjusted				
Overall	+0.4 (-1.2;1.9)	NA	+0.1 (-2.7;2.9)	NA
Length of stay ≤ 6 months ^a	+5.3 (2.8;8.1)	NA	-5.4 (-9.9;-0.9)	NA
Length of stay > 6 months	-1.1(-2.8;0.5)	NA	+2.3(-0.9;5.5)	NA
Adjusted for other possible covariates ^b				
Length of stay ≤ 6 months	+4.5(2.8;6.3)	Patient ever expressed wishes about medical treatment (+)	-2.0 (-6.6;2.6)	Patient more competent to take decisions (+) and female patient (+)
Length of stay > 6 months	-1.2 (-3.0;0.6)	None	+2.3(-0.7;5.4)	None

EOLD-SWC= End-of-Life in Dementia – Satisfaction With Care (range: 10-40); EOLD-CAD = End-of-Life in Dementia - Comfort Assessment in Dying (range 14-42). Higher scores reflect higher satisfaction and more comfort respectively. b = coefficient in GEE regression.

^a The length of stay of 39/144 patients with an EOLD-SWC score was ≤6 months and for 105 patients length of stay was >6 months. EOLD-CAD scores were available for 23/83 patients with a length of stay ≤6 months and for 60 patients with a length of stay >6 months.

^b Adjusted for other possible covariates: physicians' judgment of illness severity, dementia severity, patient specific religious background, family judgment about patient's competence to make decisions on medical treatments, patient previously expressed wishes about medical treatments, physicians' prediction (one year or less), patient age, patient gender, and family member educational level.

DISCUSSION

This study shows that families of patients were more satisfied with end-of-life care when a comfort care goal was established shortly after admission than when another goal or no goal was established. We found this pattern only for patients

who died within 6 months of admission. The quality of dying was not related to a comfort care goal shortly after admission.

The results of the current study are consistent with other studies with regard to family satisfaction with end-of-life care expressed after death of their loved one. Two studies found that families of dementia patients who received hospice care reported higher overall satisfaction with care than family of patients who did not receive hospice care.^{11,12} In the study of Teno et al., analyses were adjusted only for demographics. Another study found that families had higher EOLD-SWC scores (were more satisfied) 6 months after the start of a structured palliative care intervention compared to usual care.³¹ The palliative care intervention included a face-to-face structured conversation about end-of-life care options with two members of an on- staff palliative care team and follow-up telephone calls every 2 months.

As we only found an association with satisfaction with end-of-life care for patients who died within 6 months, which is comparable with the period that hospice care is given, the potential benefit of establishing a comfort care goal at an early stage may be larger for families when the patient will die in the foreseeable future. On the other hand, the families of patients who have no comfort goal may have been overwhelmed at that point, and we do not know whether an attempt to establish a comfort goal sooner would have produced a similar benefit. Furthermore, care goals may have been adjusted and revised to comfort care goals for those who survived longer, but our focus was on the early establishment of comfort as the main care goal.

We found no association between having a comfort care goal shortly after admission and quality of dying; similarly, Shega et al.¹¹ found no differences in pain or other treatable symptoms between patients who received hospice care and those who did not. In that study, regardless of hospice enrollment, all patients received care from one institution with extensive experience in providing palliative and end-of-life care. Teno et al.,¹² on the other hand, found higher quality of dying ratings on a 10-point scale in families of patients who received hospice care. However, in our earlier research, the validated 14-item EOLD-CAD scale did not correlate well with an overall quality of dying rating.²¹ Perhaps the overall rating captures a different perspective that more strongly includes satisfaction and expectations than the EOLD-CAD.

Establishing a comfort care goal shortly after admission in itself does not guarantee a comfortable death. The World Health Organization (WHO) definition of palliative care refers to treatment of symptoms to improve comfort.⁷ In spite of the presence

of physicians in Dutch NHs,³² ACP may focus disproportionately on limiting treatments rather than on what can be done to improve comfort. Furthermore, earlier, we demonstrated that family perception of the quality of dying, as measured with the EOLD-CAD and other instruments, is better in the United States than in the Netherlands,³³ so there is room for improvement. Nevertheless, perhaps not all symptoms can be relieved despite optimal treatment and monitoring of symptoms, and potentially, better physician–family communication about possible symptoms even leads to families reporting more symptoms resulting in lower comfort scores.

Recently, we showed that comfort at the end of life is better for dementia patients whose families recognized dementia as a disease you can die from shortly after admission.²⁹ In addition, Heyland et al.³⁴ found that discussions about the prognosis of patients with cancer or end-stage medical disease may improve family satisfaction with end-of-life care. Talking about the prognosis and raising family awareness that dementia is a disease you can die from may be beneficial. However, as we found that death within 6 months was often not foreseen even by the physicians on the staff (the physicians predicted death in 8.8% of cases, while 33.8% of all patients died within 6 months), considering a comfort care goal shortly after admission may be a more rational approach that can help improve care or increase family satisfaction with end-of-life care. However, not every family is receptive to discussions about comfort care, so individual preferences and factors known to relate to timing³⁵ should be taken into account when determining the best moment to discuss comfort care.

In addition, we found that families were more satisfied with care when a patient previously expressed wishes about medical treatments. Expression of wishes is a part of ACP, and Detering et al.³⁶ reported that ACP in older people related to higher family satisfaction. However, there is little evidence regarding the effectiveness of ACP specifically for people with dementia.³⁷

Strengths and limitations

The strength of this study is that associations with family satisfaction with end-of-life care and quality of dying were examined prospectively, and we adjusted for probability of receiving a comfort care goal.²² However, residual confounding is possible and causality cannot be inferred from observational data. We lacked a full account of all treatments provided, and we could not identify effectiveness of treatment to improve comfort in our observational study. We recommend future research on the relation between care goals, treatments provided, and comfort after death. The EOLD-CAD was only completed by family members who were present at death, which resulted in a low number of EOLD-CAD ratings. However,

almost all families who were present at death also completed the EOLD-CAD (83/87), and there was no difference in EOLD-SWC scores based on being present at death or not. In addition, the 30 patients without a family after-death assessment resulted in a smaller sample size and suboptimal power.

Our study was conducted in a country in which specialized physicians are highly present in NHs, and Dutch families may have less influence on the decision-making process as compared to in the United States.³⁸ A highly present physician can intervene quickly if someone seems to be less comfortable, and may do so regardless of the exact care goal. However, with more distant physicians, nurses might rely more on the care goal in consulting the physician about treatment. We therefore recommend further research in countries with other models of care and with a larger sample size.

Conclusion

A main care goal aimed at comfort established shortly after admission may improve family satisfaction with end-of-life care of patients who die within 6 months of admission. No such association was found for quality of dying. Given that death is difficult to predict, family caregivers should receive support to discuss care goals if appropriate and at least consider a comfort care goal upon admission. Establishing a comfort care goal at an early stage may be important to the family, and possibly even more important than for the patient in a context of continuity of care and physician presence as in the Netherlands. ACP interventions should be studied for their effects on patient outcome and family outcome, which may include family satisfaction and well-being.

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DECLARATION OF CONFLICTING INTERESTS

All authors have no conflicts of interest to declare.

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